Stories from the fourth age: autonomy and the lives of older care home residents

Abstract

Transition to a care home often follows a hospital admission and can be distressing. Care home settings play an important role in the care of many people at the end of life. This longitudinal study employed a narrative approach, aiming to explore the perspectives of older care home residents on transitions to, and life and death within, care homes. Five participants, aged 85 years and over, were recruited from two privately owned care homes in the South West of England. All participants had a diagnosis of an advanced progressive condition (excluding advanced dementia), or were thought to be frail. Longitudinal interviews (19 in total) were conducted over a ten-month period. A structural narrative analysis was performed and participants' narratives are presented under 3 headings, with one participant's story chosen to illustrate each narrative type: 'becoming a care home resident', 'living in a care home' and 'death and dying'. Findings revealed that care home residents experience a loss of autonomy and a lack of agency; they are often excluded from decision-making. Older care home residents have few choices with regard to care at the end of life. Further work is required to improve transition into care homes, including support and advocacy during decision-making, which often takes place in hospitals at a time of crisis.

Key words

Older people, care home, decision-making, autonomy

Introduction

Over 111,000 people in England died in a care home in 2017 (Public Health England 2019) and a third of this group were classed as temporary care home residents (where death occurred in a care home, but the postcode of residence on the death certificate did not match a care home) (National End of Life Care Intelligence Network 2017). More than half (56%) of people, newly admitted to a nursing home, can be expected to die within 12 months (Kinley *et al.* 2014).

The transition into a care home is a significant life event and has been described as an 'event horizon', from which there is no way back to a former life (Higgs and Jones 2008). The term 'fourth age' has been used to describe this final phase of life, defined by a loss of agency over body and identity, and representing an enforced dependency. Those within the fourth age become objects of others' discussions and live within others' rules (Gilleard and Higgs 2010, Lloyd *et al.* 2014). The imposed routines and loss of control and independence associated with the move into a care home undoubtedly challenges older adults' adjustment (Wiersma and Dupuis 2010) and the term 'relocation stress syndrome' is often used to describe the physiological and psychological stress a person suffers as a result of this transition (Manion and Rantz 1995). However, some older people describe a more positive experience, suggesting that distress, deterioration, and hopelessness can be reduced by supportive relocation practices (Castle 2001).

The aim of the longitudinal interview study presented within this article was to give voice to those in the fourth age, learning about their perspectives on transitions to, and life and death within, care homes, and offering insights on how we might improve their involvement in decision-making about their care and health.

Methods

Design and Setting

The research for this paper was conducted as part of the lead author's academic clinical training, funded by the National Institute for Health Research.

This longitudinal study employed a narrative approach, aiming to gain valuable insights into the process of ageing within the care home environment. In contrast to thematic analysis, narrative analysis:

- Focuses on stories
- Tends to be less formulaic
- Does not usually involve data coding.

The research team comprised of the principal investigator (LP) and two researchers (AM and FD), all of whom were medical doctors, supported by two social scientists (FM and LW).

Given the depth of inquiry and the use of repeated interviews, the initial sample size was five participants. One participant (George, see Table 1) was withdrawn during the third interview due to concerns about his cognition and health. No data is presented here from his interviews.

Participants were recruited from two privately owned care homes in the South West of England. Care homes were invited to participate by the local authority Adult Commissioning Service Manager, who circulated details of the study to the owners and managers of local care homes. Care home One was an adapted period property, situated in a rural village, and provided nursing and personal care for up to

48 people. Care home Two was purpose-built and situated in a town, accommodating 55 people who required nursing or personal care.

Participant recruitment

Potential participants were identified through discussion with the care home managers. Inclusion criteria were:

1) Age 85 years or over
2) Advanced progressive condition (excluding advanced dementia) or thought to be frail
3) Capacity to consent.

Potential participants were invited to talk through the study in person with one of the researchers. An information leaflet was provided so that they could discuss it with family or carers if they wished. A week later the researcher returned to obtain written consent, at which point a capacity assessment was undertaken; this included an assessment of whether the person was able to understand the information given to them about the study and retain that information for long enough to be able to decide whether to participate. Researchers sought to clarify that the person could effectively weigh up the information available to make the decision and they were required to clearly communicate this decision. At each interview the participants' capacity was reassessed and verbal consent re-obtained.

Data collection

A series of topic guides were developed, in consultation with older people resident at a local rehabilitation centre. They were designed to be used consecutively, giving a spiral structure to the interviews. This allowed the researchers to revisit similar topics, introducing issues of increasing sensitivity, acknowledging the non-linear

nature of narrative analysis and enabling varying narratives to emerge. This iterative approach allowed the topic guides to be amended according to data collected during previous interviews. Topics included past and current relationships, health concerns, discussions around future care and thoughts on death and dying.

Each participant was interviewed up to five times over a ten-month period, between February and December 2015, with each interview lasting 30-45 minutes. Interviews were conducted in the participants' room. Re-interviewing participants over an evolving period encouraged reflexive thinking and allowed exploration beyond the 'public accounts' that are shared between strangers (Cornwell 1984).

With participant consent, the interviews were audio recorded, anonymised and professionally transcribed verbatim. Nineteen interviews were conducted and transcribed for analysis, with data from 16 presented here following the withdrawal of George from the study.

< Insert Table 1 about here >

Analysis

A structural narrative analysis was performed, exploring the types of narrative that the participants drew on to shape their stories. After initial readings of the transcripts, the principal investigator (LP) generated an individual narrative for each participant, summarising the conversations over the course of the study. This enabled the stories to be brought together in one place. The narratives were compared to see if there were commonalities in the types of stories they told to shape their experience and in order to make meaning.

A typology of narratives was then constructed and refined, through discussion with other team members, to organise and present the participants' stories (Phoenix, Smith and Sparkes 2010).

Results

Participants' narratives are presented in relation to three life events or stages:

1. Becoming a care home resident
2. Living in a care home
3. Death & dying

Data is presented here under the three headings above, with an individual participant's story being chosen to illustrate each narrative type. This way of presenting research findings is commonly used in narrative research to preserve complexity and allow a greater attention to detail (Riessman 2008).

In addition, in order to represent some of the findings in a visual manner, a series of five illustrations were commissioned by a local artist with the aim of bringing the data to life and making it more accessible to a lay audience. The artist and LP worked together to identify key messages from the data. Two illustrations, which include direct participant quotes, are displayed in the results (Figures 1 and 2).

Becoming a care home resident: 'Reluctant relocations'

Several participants recounted 'reluctant relocation' stories, expressing feelings of loss of autonomy and a lack of agency. They told stories about being excluded from

the decision-making process, with others, often family members, having the final say in the outcome.

William

William was born in 1922 and was 92 at the time of his first interview. He was very proud of the time he spent in the RAF during the Second World War and recounted his memories of this at each interview. After the war he joined the civil service and married the sister of one of his friends. William and his wife had four children but, sadly, one of their daughters died when she was only 5 years old. His wife died very suddenly when they were both in their 70s, “dropping dead” in the kitchen whilst he was at work. He described this as a terrible shock to the whole family. William talked about how, prior to the decline in his health, he would cook for himself and make his own jam from the fruit in his garden.

Whilst still living in his own home William had several strokes, severely affecting both his speech and his mobility. He had moved into the care home near to where his daughter lived, a year before, but didn’t consider it to be his home. This transition was precipitated by a hospital admission due to pneumonia. He did not return home after discharge. During our interviews he sat in a chair opposite a picture of the home he moved from, many miles away, and described how he had felt excluded from the decisions about his future.

> *“This isn't my home, and if you look up there [pointing at a picture] the bungalow on this side of the pair used to be my home... But I came here last Christmas. The family spoke to me and said I shouldn't be looking after myself, and lots of people I know had a meeting, there must have been ten*

against me, we had a vote. I was the only voter on my side... And we argued and argued for about four weeks, and in the end they beat me."

< Insert Figure 1 about here >

William's narrative sought to make sense of a 'reluctant relocation' and in the first interview he was keen to stress how independent he had previously been, although recognised that he had been beginning to find things more challenging:

"I was managing… At the time, I'd been in hospital with pneumonia I think, and I was getting older. And I had to realise I wasn't getting any younger, and whilst I was looking after myself entirely, baths and breakfast, tea… No, even the Christmas before last I could cope. If I was honest, I wasn't coping as well as I'd coped not too far back... I think, being fair, my son, and probably my daughter, had accepted that they didn't do the right thing. But having said that, if I was thinking about it, I could as well have known that I was going down the hill."

William highlighted the tension between a desire to preserve his own autonomy and the wishes of his family and carers to keep him safe. This tension presented itself in a multitude of ways throughout the interviews.

William had his own telephone next to his chair and, several times during the interview period, he (appropriately) contacted the research team directly to find out when they were coming. He explained that, despite having access to a telephone, he was not able to make direct contact with a doctor when he felt that he needed to see one. The barrier to this was unclear.

"And you can't get in touch with the doctor. Hopeless. I can only do it through the carer."

Whilst he recognised that his strokes had affected his mobility, William felt that the biggest deterioration had occurred since entering the care home. The desire to keep him safe had, he believed, been prioritised over his ability to walk.

> *"I was a bit doddery anyway…It wasn't as though I'd suddenly stopped walking…. Well, it [mobility] went downhill very, very quickly… I was put in a chair like this. I never walked about, or if I tried to do I was immediately bunged back in my chair, and told to wait for three people. God knows what three people would do for you..."*

Living in a care home: Health and agency

Continuity of care is of increasing importance as we age and develop greater health needs, and yet interactions with healthcare professionals can be difficult for older people.

<u>John</u>

John was 94 at the time of first interview. He lived on the first floor of the care home in a twin room which he shared with his wife, Mary*. John and Mary met in 1944 and married a year later. He had not joined the armed forces during the Second World War due to a disability, acquired as a result of polio infection as a young child. John and Mary had three children; their youngest son continued to live with them and took early retirement in order to provide all their domestic and personal care. When Mary's health deteriorated, and her care needs became too great for their son to cope with, John decided that he would move into the care home with her, even though his care needs were not so great.

In his second interview John talked about his experience of having a transient ischaemic attack and the care that followed this, which occurred about 16 years beforehand. He was able to remember in detail the day that this happened and the discussion he had with the vascular surgeon who proposed to perform a carotid endarterectomy.

> *"… they explained to me that if I have nothing done, I'll have mores strokes coming on, so that finally I get a big one. So I said 'well I will have that then'. He said you can have two ways of operation, you can have it done by anaesthetic or you can have it done by, what they call when they freeze it, what do they call that?… Local anaesthetic, that's right."*

Despite this prior engagement with decision-making, in our third interview he demonstrated a lack of involvement in his current healthcare, with others making decisions about, and speaking for, him.

> *"I am giddy at times. In fact I said it to the nurse and she is going to see the doctor… I always thought I had high blood pressure. I think I still did used to have high pressure; I used to have a pill to keep it down a bit. Then a few months ago I had a fall, didn't I? Over there, and I cracked the back of my head. They said, 'His blood pressure has gone the other way.' It was too low. Well now, I had a pill for too low a blood pressure and I don't know whether I still have got it. The nurse comes in and gives me these pills, and I don't know what they are… I think I'm getting giddy a little bit too much and it has never been sure why I should be giddy. She said, "We'll ask the doctor." So she'll be in and she'll take my blood pressure or whatever they do to see what they want altering."*

Later, John explained that he, like many older people, wasn't clear about what medication he was taking, or why.

> *"I have been cut down by the doctor. I used to have a dickens of a lot of pills, I think I did, and she cut them all out and then she started from scratch again. I have four tablets a day, that is two large ones and two tiny little things, and that is my lot. That is all I have, but I don't know what they are. The nurse comes in and gives them to me. I haven't got a clue what they are… I would like to know, but what's the good? I wouldn't remember it anyway [laughs]"*

< Insert Figure 2 about here >

Living in a care home: The 'good resident'

Care home residents rely on care home staff for even the most basic things, such as food and personal care. Some residents created narratives that portrayed them as being easy to care for, possibly to obtain better care and claim 'good resident' status.

Dorothy

Dorothy was born in 1919 and was 96 at the time of her first interview. Until a couple of years before she had been living independently in a flat in the West Midlands. She talked about how she had met her husband at a holiday camp when they were teenagers and then subsequently married in 1940, just before he was sent away to fight in the Second World War. They had one daughter together after he returned. In recent years Dorothy had cared for her husband as he became increasingly frail. She explained that he had died suddenly, in her arms, six years ago, after suffering with a chest infection.

One night, a couple of years ago, she fell trying to pick up her phone and ended up being stuck in a chair overnight. Neighbours found her in the morning and called an ambulance, which took her to hospital. During this admission she began to lose interest in things and her daughter became concerned, so brought her to live with her. However, following another hospital admission, she moved to live in the care home. Dorothy's narrative was one of seeking to appease and not be a burden.

She talked about why she had felt compelled to move from her daughter's house into the care home.

> *"I felt I must you know [move in to the care home], because she'd got to live her own life you see."*

In her second interview Dorothy refers to herself as a "good patient":

> *"Every day at home I used to have a slice of lemon with hot water… well I don't bother them now, you know. They would get it for me, but I don't bother. I just have a cup of tea when I ring them... I'm not much trouble to them at all. I don't ring that bell for them very much, only for a cup of tea in the mornings, you know? But no, they say I am a good patient."*

She also talked about how she had dealt with the death of her husband, long before entering the care home, by hiding her true feelings so as not to burden others:

> *"I could have been really a lot worse, but you've got to make the most of these things and move on with life but it takes a long time and yeah people say 'Are you alright?' You say 'Yes' but you're not, [laughs] you know. But you keep that to yourself, don't you? Well, I did anyway. Because I'm a person like that. I think other people have worse troubles than me. Everyone's got troubles,*

haven't they, and so, you know, you don't have to burden them with your troubles. That's how I feel."

Although it would appear that she has always been someone who doesn't like to trouble others, it is interesting to speculate about whether this narrative had been partially created in response to her experiences in hospital, prior to entering the care home, where the care was not responsive and she was admonished for requesting basic care.

"Well they didn't talk very much to you… but I mean if I wanted to go to the toilet, they said 'oh you are ringing at the wrong time, you always ring when you've got visitors'… and things like that and they didn't used to come so quickly when I rang the bell if I wanted to go to the toilet…"

Death and dying: Not much choice

Many of our participants chose not to think about death and their narratives were of a state of ambivalence, with little forward planning, lack of knowledge of advance care plans and lack of discussions of their wishes with family, despite knowing that death was inevitable.

Margaret

At 86 years old, Margaret a retired GP, was our youngest participant. She had lived in care homes for five years. Many of the stories she told related to regrets and negative experiences in her life, including feeling like a disappointment to her parents, not fitting in to medical school and in her career as a doctor, her husband's

infidelity, and her relationship problems with her daughter. She described herself as having “always been rather moody”.

As a doctor, she is likely to have been exposed to more death and dying than the average person. During her first interview she reminisced about her early experiences of learning anatomy at medical school, from cadavers.

> *“Then of course, well, I didn’t really know a lot about medical training, but we sort of shot into the anatomy department and I suppose… it’s a bit of a shock you know… Well sitting round a dead body… I was put in with some boys, or young men and I don’t know – medical men get rather detached from everything, don’t they? I think doctors are a funny lot really.”*

She then shared her experience of losing her husband:

> *“I was sixty-four when Stanley* died… He just dropped dead on the … he was cutting grass and I was at work at the time; they rang up and got a message through to the health centre that my husband was dead. Well… he wasn’t terribly fit but it was a shock because he wasn’t really ill… I was out working 10 miles away. I said to him, ‘Would you like me to come home at lunchtime?’ He said, ‘It doesn’t seem worth coming all that way.’ That was the last thing he ever said to me.”*

In her second interview she demonstrated a fatalistic view of death and her views on how she might die.

> *“Well, I sort of expect that sort of thing to happen, really. Either a stroke or a heart attack… unless I’m one of these – when you hear of people dying in their sleep or anything. But that doesn’t happen – I wouldn’t think that*

happens as often as a stroke and that… It's going to happen. It's got to happen, hasn't it?"

She told the story of watching another patient die during one hospital admission and her willingness to leave it up to others to decide her care.

"A lady on the ward died of pneumonia or a chest infection or something and they just left her, they didn't give her any drinks or anything, I thought that's not very nice. You know because if you go on feeding people they live longer, but she was peaceful. I don't mind leaving it to the professionals to do what they think really, because they've got to do it anyway so..."

When asked if she would want to be resuscitated, she again demonstrated a philosophical stance.

"No I don't want to be, well I suppose if there was something that was stuck in your throat or something, so to free an obstruction I would want them to do that if they can, but I mean if you are sort of unconscious or you had a serious thing like a stroke or heart attack then I don't think you would want to be resuscitated... You have got to go at some time, haven't you, there's no point in, there comes a time when there is no point doing that."

In the final interview she talked about her thoughts on how she would like to die and how she was unlikely to have much choice where she died.

"I think the worst sort of death must be after injuries and things, or like you see in films sometimes. People are shot, or something, and sort of fading away. No, I don't think death is to be feared, really, because you can't do anything about it, can you? You can't stop it happening…Obviously, [a good death is] when you don't sort of know it's happening, like in your sleep or

something like that. You don't want to be fighting it, do you? You don't want to be sort of struggling or fighting anything."

"But I don't think there is much choice between the care home and the hospital for dying, I don't think there is much choice… I don't think one is better than the other, because the hospital is similar isn't it, there is a lot of people, different people and that. You know there is like a multitude of everything, ages, nationalities, everything looking after you… the way I feel at the moment I prefer care home to hospital because I feel perhaps a hospital is a bit impersonal, but on the other hand they tend to you quicker. But I wouldn't like to be in a hospital now. The last time I have been there I was thinking care home would be more comfortable."

Margaret had a good understanding and insight into the realities which might face her in the future. She was happy to have full and frank discussions about her own death and preferences for her care, whilst recognising that her choices might be limited.

Discussion

This narrative study, involving longitudinal interviews, explored the experiences of four care home residents in relation to their transition into the care home, what it means to live in a care home and around death and dying.

Although the NICE guideline, "Transition between inpatient hospital settings and community or care home settings for adults with social care needs" (National Institute for Health and Care Excellence 2015), states that a patient-centred approach should be an overarching principle, our findings show that older care home

residents often feel disempowered. Many of our participants told us that they had disagreed with the decision to move into a care home, but their views were not listened to or considered.

Discharge planning meetings are widely used on care of the elderly wards in the UK. Our findings, exemplified by William's narrative, suggest that this process can represent a tokenistic approach to patient participation, and having the patient present does not guarantee genuine involvement. This is supported by a recent Scottish study exploring discharge decision-making with older people in hospital, which found an "absence of the older person's voice in a decision which is life changing" (Rhynas *et al.* 2018).

Studies suggest that older people who have greater control over the decision to move feel more satisfied and can adjust more quickly (Young 1998). 'Reluctant relocation' narratives may inhibit this process of adjustment by reinforcing a sense of disempowerment and dependency (Reed *et al.* 2003). We would argue that discharge planning meetings must have an overt agenda, developed in consultation with the patient and their family. Etkind *et al.* (2019) suggest that clinicians should discuss with patients what is an achievable normal in the context of what matters to that individual, and then discuss care in relation to this to maintain identity and dignity in their daily life.

Our findings show that some care home residents, such as Dorothy, want to be seen by their carers as 'good residents'. Jeffery (1979) described two categories of patients attending hospital casualty departments, as reported by the medical staff, as being either "good" or "rubbish". Rubbish patients were often made to wait longer for their treatment, treated with less sympathy and, sometimes, verbal hostility from

staff. It is possible that a similar categorisation, or at least the perception of such, exists within the care home environment.

In a study of older people living in their own homes, Lloyd *et al.* (2014) suggest that their engagement with their health issues helped to "maintain their agency and provided shape and direction to their everyday lives". In contrast to this, our participants described a lack of engagement with their health and its management, which most commonly manifested as poor knowledge of their medication regimen. This is likely to be due to many factors including poor health literacy, which has been shown to decline with increasing age (Baker *et al.* 2000).

Despite continuity of care being highly valued by patients with multimorbidity, such as those who are resident in care homes, Salisbury *et al.* (2011) have demonstrated that they are less likely to receive it. At a time when this continuity is perhaps most important, many care home residents are required to register with a new GP on admission, often leaving behind a trusted GP who may have known them and their family for many years. This is also likely to contribute to disengagement with the management of their health.

End of life care rhetoric often focuses on choice, particularly related to preferred place of death, however it has been suggested that care home residents have no "chosen choices" (Gilleard and Higgs 2010). Choices they appear to have about food, clothing, what time to get up, and where to die, are created by the institutions and those working within them. This sense of a lack of choice was clearly expressed by Margaret in her interviews.

We know that most (70%) permanent residents of care homes die in the care home (Pocock *et al.* 2016, National End of Life Care Intelligence Network 2017) and that

advance care planning for older people is particularly challenging. This is due to the complexity of their preferences, which are subject to change over time and dependent on their circumstances (Murtagh *et al*. 2012). The process should therefore be carried out by skilled professionals who understand the care home context and can help them to express their preferences with sensitivity, providing regular opportunities to re-visit these discussions as things change.

Strengths and limitations

Qualitative research relies on those who conduct it. In this study, all three interviewers were medical doctors, and this was disclosed to participants. This may have had an impact on how and what the participants said in their interviews, as participants may have been more likely to give "public" accounts due to the social dimensions of power within the research interview (Cornwell 1984). Confusion about the role of the researcher may also have caused Margaret's suspicion when, after complaining about the quality of care she was receiving in the care home, she stopped FD to clarify that she was not working with or for the care home.

We have attempted to maintain a reflexive approach, which has been aided by a multidisciplinary research team.

The credibility of our findings can partly be based upon the richness of the data. In this study, data is presented from four older persons, each one interviewed at least three times during a ten-month period, with data from a total of 16 interviews presented here. Our findings complement the outcomes from previous work and provide a useful insight into how this population experiences the world.

Conclusions

The narratives presented here suggest that more could be done to improve the process of transition into a care home and to promote and facilitate autonomy and dignity. This could include more support and advocacy during decision-making, which often takes place in hospitals at a time of crisis. Increased funding and training for those who provide care at home might also facilitate older people staying in their own homes for longer, thus maintaining their autonomy.

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Table 1. Participant characteristics and interview details

Care home	Pseudonym*	Age at first interview	No of interviews	Time in care home at first interview	Interviews conducted by
One	William	92	5	10 months	LP/FD
One	Margaret	86	4	20 months	LP/FD
One	George	93	3	11 months	LP/FD
Two	John	94	4	14 months	AM
Two	Dorothy	96	3	16 months	AM
Total number of interviews = 19					

*Pseudonyms were derived from records of popular baby names in the participant's year of birth

Figure 1. We had a vote

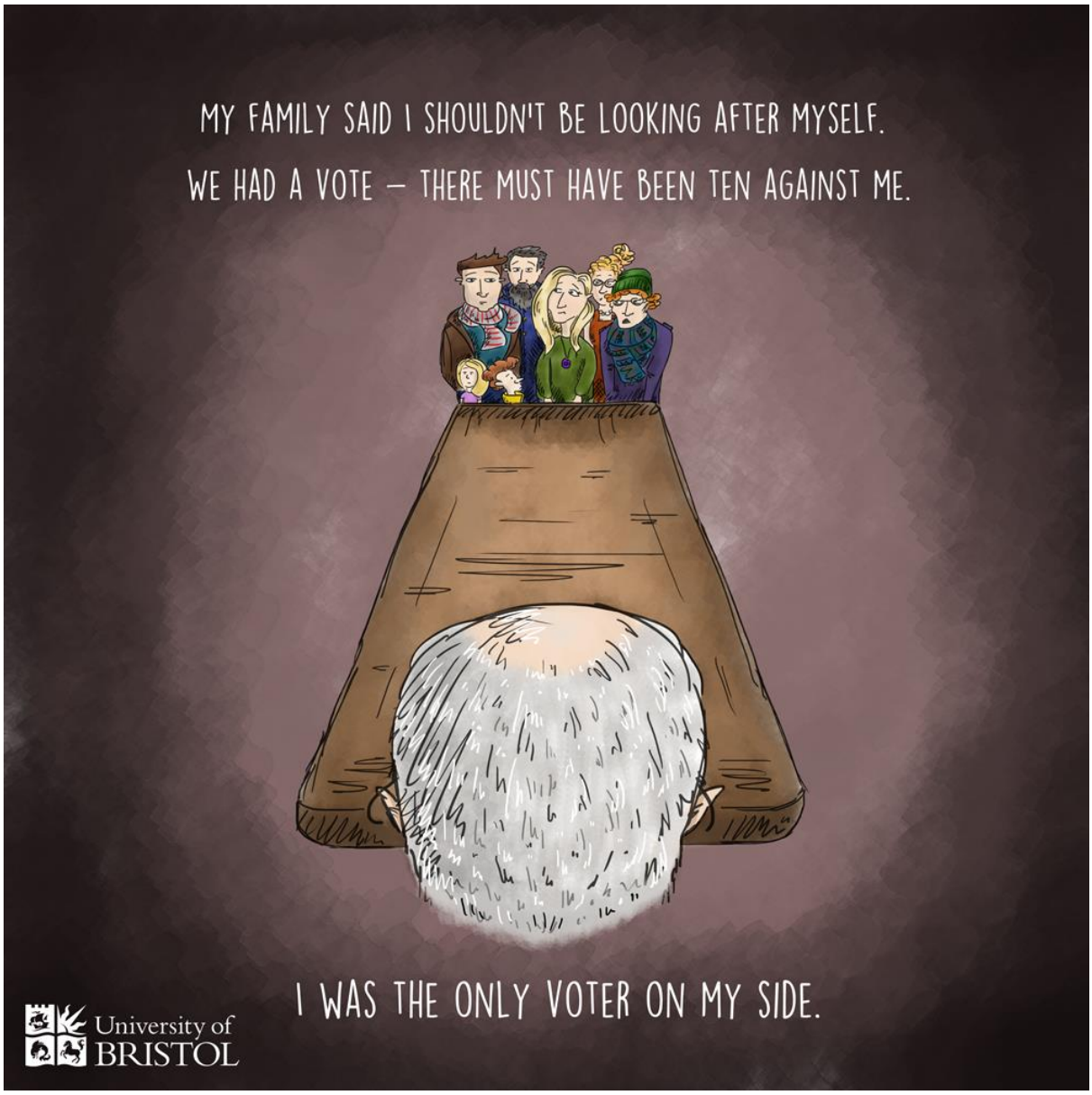

Figure 2. I haven’t got a clue